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AUTHOR Strobino, Jane
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ABSTRACT

The study addresses parental coping patterns of children with congenital heart disease in the state of Hawaii. Attention was given to geography and ethnicity as well as parental and child characteristics as factors impacting on the coping pattern. Telephone interviews with parents (N=32) obtained data concerning parent characteristics, their perception and utilization of formal and informal resources, child characteristics, family life and family relationships, social support, and understanding of the medical situation. Among findings were that this sample of children was not substantially disabled by their heart disease, that 60% of parents anticipated complete recovery of their child, and that coping mechanisms focused on family integration and understanding the medical situation. The questionnaire used, "Coping Health Inventory for Parents" was judged to be appropriate for clinical assessment of this population. (DB)

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Coping Behaviors of Parents with Children with Congenital Heart Disease

Paper Presented at the
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Jane Strobino, D.S.W.
Assistant Professor
Marywood College
School of Social Work
Scranton, Pennsylvania 18509

EC 211002

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Background

Congenital heart disease is considered to be the most frequently diagnosed pediatric cardiac condition (Travis, 1979). Such a diagnosis has wide variation in terms of degree of severity, potential for corrective treatment, and ultimately the ongoing and overall development of the child. The particular defect may be self correcting, require corrective surgery, or may not be amenable to surgery and have a poor prognosis for recovery.

Given that the diagnosis of congenital heart disease usually is made at birth, parents face a variety of challenges not only in their role as parents but in their new and central role as managers of the child's cardiac condition. Such a role can extend over a number of years and involves physical, economic and psychological adaptations to this non-normal situation.

Chronic fatigue may occur, especially in the mother as a result of meeting the child's regular day to day needs as well as the child's special medical needs. These special medical needs can include regular and often distant visits to the pediatric cardiologist, compliance to a particular treatment regimen at home, and emergency medical care.

The costs of treatment for the child, including medications, equipment, physician's fees and hospital costs can be overwhelming even with health insurance.

The psychological impact may involve continual unanswered questions about the reason for the diagnosis and situation, and concerns about recovery or relapse.

In meeting the challenges of caring for a child with congenital heart disease, parents can access both formal and informal support services. Formal support services may include: financial assistance, local support groups, respite care and transportation. Informal support services, comparable to formal services only provided by friends, neighbors or other family members, also can be of help to parents.

Both social work practice experience and the literature document a variation in how parents manage the responsibilities in raising a chronically ill child (Caroff & Mailick, 1985; Cloutier & Measel, 1982 ; McCubbin, Cauble & Patterson, 1982). Variables relating to both the child and the parents are important to consider in understanding the coping patterns of parents. The child's age, age at the time of diagnosis, the number of surgeries he has had or will have to have, the need for medications, the limitations in activity imposed by parents and physician and the frequency of clinic visits are important variables in gaining an appreciation of the severity of the condition and the corresponding impact on the parents for caregiving.

Variables pertaining to the parents add further information which enhances our understanding of their coping patterns. Their age, ethnicity, religious affiliation, marital status, socioeconomic status, level of education and use of supports all may impact on the coping pattern that the parents utilize in caring for their ill child.

Three particular coping patterns have been identified by McCubbin, McCubbin, Patterson, Cauble, Wilson, and Warwick (1983) in their research with parents of chronically ill children. These coping patterns focus on family integration, social support and self-esteem, and understanding the medical situation of the child.

Given the role that parents play in managing the needs of their children with congenital heart disease, it is important for service providers in general and social workers in particular to know the coping patterns that are facilitative so that these patterns can be enhanced or supported.

In the State of Hawaii, there are two factors which may have some important impact on the coping patterns of parents. These factors are ethnicity and geography. The ethnic diversity prevalent in the State may impact on how parents view the diagnosis and subsequently on how they use formal support services. Language may also create a barrier to understanding of the diagnosis and accessing services. Geographically, due to the island makeup of the State, travel between islands is costly and families can remain isolated from formal support services. All of the islands have fairly extensive rural areas which contribute to limited access of support services.

Thus, this study addressed parental coping patterns with children with congenital heart disease. Attention was given to geography and ethnicity as well as to characteristics of the parents and the child as factors which have potential for impacting on coping pattern.

The Agency

The Crippled Children's Services Branch of the Hawaii State Department of Health provides diagnostic and treatment services to children with congenital heart disease. Diagnostic services are available to all children, however treatment services are available to only those children whose families meet specific financial eligibility requirements. Treatment services include a range of medical, nursing, and habilitation services as well as social work services. Monitoring services are ongoing. Although services are based in Honolulu, clinics are scheduled regularly on the three neighbor islands.

The Study

This was a one group exploratory study of a population of parents whose children were patients of the cardiac clinic of the Crippled Childrens' Services Branch located in Honolulu, Hawaii. The study attempted to answer the following questions: (1) What coping patterns do parents report in the management of their children with congenital heart disease?; and (2) What variables might be associated with these coping patterns? Consequently two major factors were investigated, the coping patterns/styles of these parents, and the demographic characteristics of the parents and their children with congenital heart disease.

The population pool included all those families who were registered with the Pediatric Cardiac Clinic of the Crippled Childrens' Services Branch. A random sample of seventy eight (78) names were selected by a computer program from an alphabetic listing. Of these 78, thirty seven (37) names had to be discarded due to: lack of current telephone numbers; lack of response to telephone calls; lack of understanding of English; and the unavailability of the primary caregiver to respond to the telephone interview. Thirty two (32) parents whose child did have congenital heart disease did participate in the study. Noteworthy is the fact that among those families who could be reached for participation in the study, there were no refusals.

Prior to the initiation of the telephone interviews, a letter was sent to all potential subjects by the Director of the Crippled Childrens' Services Branch. The letter informed the parents of the study and afforded them an opportunity to refuse to participate. Telephone interviews lasting between forty (40) and ninety (90) minutes were conducted during January and February, 1987 by two research students.

Two separate instruments were used to collect the data. One instrument was a demographic type questionnaire that included items about the characteristics of the parents, their perception and utilization of formal and informal resources, and characteristics of their child with congenital heart disease. The other instrument was a standardized questionnaire called the CHIP - Coping Health Inventory for Parents which assessed how parents manage family life when one member has a medical condition that calls for continued care (McCubbin et at., 1983). The CHIP contains forty five (45) items relating to behaviors along three separate dimensions: (1) family life and family relationships; (2) social support; and (3) understanding the medical situation. The instrument, as developed by McCubbin and his associates and was noted to have an acceptable reliability ($r = .86$).

A number of methodological factors pose limitations to the results of the study. The small N size of the sample does impact on the ability to document statistically significant

relationships and to generalize the results to the larger population of parents with congenital heart disease. Some of the items on the CHIP questionnaire were unclear to the respondents and the length of that questionnaire may have resulted in response set bias by some of the participants. Despite these limitations, the data obtained from this study does allow us to address the research questions and provides valuable information about the coping patterns of a multi-ethnic sample of parents. Such information can be used as a consideration in determining social work treatment with families of children with congenital heart disease.

Findings

The findings of this study are presented according to the characteristics of the children with congenital heart disease, characteristics of the parents, and coping patterns.

Children with Congenital Heart Disease

Table 1 summarizes the characteristics of the children with congenital heart disease. The children ranged in age from less than a year old to seventeen years of age with the average age being five years. There was almost equal numbers of males and females represented in the sample. Over ninety percent of these children had been diagnosed at birth as having congenital heart disease, but only one third had any surgical treatment for this condition. In terms of limitations on activities, over eighty percent had never had restrictions imposed by either their parents or their physician. Currently, almost ninety percent are not taking medication for their condition and nearly two thirds have clinic appointments scheduled less than once a year.

Thus, it appears that this sample of children with congenital heart disease, on the average, does not present extraordinary demands on the parents in terms of medical and physical management.

Parents

Table 2 displays the characteristics of the parents. Eighty one percent of the respondents to the telephone interview were mothers who ranged in age from twenty to sixty five with the average age being thirty four years. Nearly two thirds of the mothers wre currently married and over ninety percent reported an income of less than $21,000 per year. The average number of persons this income supported was four. Educational achievement for this sample ranged from sixth grade to college with the average being a high school education. The majority of the respondents resided on the island of Oahu with the islands of Kauai, Hawaii, and Maui also represented in this sample.

Nearly ninety percent of the respondents reported some religious affiliation with the two main denominations being Catholic and Protestant. Hawaiian or part Hawaiian was the most highly represented ethnic group followed by the Filipinos, Mixed Ethnic Group, Caucasians and Japanese. Over eighty percent of the respondents reported informal support services readily available whereas seventy five percent reported that they currently were using at least one public community resource. Sixty percent of the respondents anticipated complete recovery of their child from the caridac condition whereas twenty five percent reported that although their child's condition was stable, there would always be a need for some type of medication or medical follow up. Finally, the respondents noted the medical services, public health nursing services, and financial assistance as the most useful services provided by the Crippled Childrens' Services Branch.

Thus, it appears that the parents, on the average, are connected with both formal and informal support services to assist them in the management of their child with congenital heart disease. Additionally, these parents demonstrate characteristics (age, education, income, and marital status) that one might assume to be consistent with the ability to provide for the needs of a chronically ill child.

Coping Patterns

In answering the items on the CHIP questionnaire, respondents could indicate the degree to which the item was considered to be helpful in the management of their child with congenital heart disease. Answers ranged from not helpful at all to extremely helpful.

Noted in Tables 3, 4, and 5 are those items for which a majority of the respondents indicated that they were extremely helpful.

Table 3 identifies those items from Subscale 1 - Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation. Given the high percentage of items (16 of 19) within this subscale noted to be extremely helpful, this coping pattern or these coping behaviors were more readily used by this sample that the other coping patterns. Clearly in this coping style, behaviors which focus on interaction with the child, and the perceptions that the medical needs of the child are being met and that there are positive aspects of the situation, are emphasized.

Table 4 indicates those items from Subscale 2 - Maintaining Social Support, Self-Esteem, and Psychological Stability, for which the majority of the respondents identified as extremely helpful. It is noteworthy that only four items of a total of eighteen items in this scale could be included in this table. Further, particular items fould to be helpful focus on

self-esteem moreso than on social support.

Table 5 depicts those items of Subscale 3 - Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff, which were found by a majority of the respondents to be extremely helpful. Obviously direct communication with the physician and other medical staff are valued most highly, followed by the parents actually carrying out medical treatments at home. Talking with other parents and reading about the medical problem are also considered to be extremely helpful.

In sum, this sample of parents reported as extremely helpful coping behaviors within each of the three dimensions of the CHIP questionnaire. Coping patterns focused primarily on Maintaining Family Integration, Cooperation and an Optimistic Definition of the Situation, followed by Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff. Finally, some coping behaviors of the dimension Maintaining Social Support, Self-Esteem and Psychological Stability were identified as extremely helpful.

In assessing the impact of ethnicity and geography in relation to coping patterns, the following results were obtained.

All ethnic groups essentially displayed comparable coping patterns, obtaining nearly equal mean scores for each of the subscales.

According to geographical location however, respondents from the island of Hawaii indicated the lowest percentage of use of formal support services and lower average scores on Subscales 1 and 3 of the CHIP questionnaire. The lower average subscale scores suggest that the respondents from the Big Island are less likely to find extremely helpful in coping, maintaining family integration and understanding the medical situation.

Discussion

Although it appears from the characteristics of the children with congenital heart disease that they present few extraordinary caregiving demands on the parents, this does not mean that information about the child is not important. Rather, it remains important to document such information early on as part of the assessment phase of social work intervention. Further, it is critical to elicit the parents' perception about physical caregiving demands in light of the child's characteristics since there is a body of literature that suggests that perception of disability can have a greater impact that the actual severity of the disability. Additionally, ongoing communication with parents is necessary if one is to assess the changing demands

that such a diagnosis can place on the parents.

These practice implications are supported by the parents' identification of coping behaviors that are extremely helpful - talking with medical staff, and carrying out treatments at home.

In terms of the characteristics of the parents, the findings suggest a group of parents who do have the capacity to meet the special demands of managing a child with congenital heart disease. As noted above, it is important to document such characteristics during the assessment phase of social work intervention. Additionally, a focus on the self-esteem of the parent and reinforcing the parents' competence to meet the caregiving demands is consistent with those behaviors identified by parents as extremely helpful - developing myself as a person, and becoming more self reliant and independent. Using an empowerment model in the treatment phase of social work intervention is expected to further reinforce the strengths that the parents present initially.

Consistent with the life model, a family approach to social work practice, and with the respondents' emphasis on family integration as a coping pattern, it is imperative that the family unit be involved in both the assessment and intervention phases. Particular emphasis may be given to reach out to the fathers early on and to engage them in both an affective and an instrumental role. It seems that an entry point for engaging the fathers is just after the birth when the diagnosis is first made and when the father is present at the hospital for the birth.

It seems that the CHIP questionnaire is an appropriate instrument that can be used during the assessment phase in order to document parental coping patterns. Such information can be used later to reassess and guide clinical practice.

If in fact, family integration and cooperation is the major coping pattern, then treatment should have a family focus. Also critical in this coping pattern is a positive outlook for the recovery of the child and thus each family member should be encouraged to verbalize goals for the child and ideas on how to facilitate the achievement of those goals.

Given the importance of understanding the medical situation as a helpful means of coping, social workers can use a variety of strategies including: facilitating direct communication between the physician and other health care professionals and the family; linking parents to other parents who have experienced comparable challenges; and providing reading materials or written summaries of parent conferences with health care professionals

In terms of implications of the findings for research, there are several. Further documentation of parental coping patterns is

necessary and it is important not only to use a larger sample, but also to include a sample that exhibits wider variation in child and parent characteristics so that assessment of demographic and perceptual variables that may relate to coping patterns can be tested.

The area of psychological burden or impact of the diagnosis of congenital heart disease on parents' caregiving responsibilities needs further exploration. Perhaps an in-depth interview protocol could be used initially to glean information about variables that might be important.

Finally, the dimension of social support was not as highly regarded as helpful as the other two dimensions. This seems contrary to experience and the literature in terms of an approach to coping. Therefore, further investigation of how social support impacts on coping is necessary.

Summary

This was a one group exploratory research study about the demographic characteristics and coping patterns of parents whose child was diagnosed as having congenital heart disease.

The purpose of the study was to document the coping styles of the primary caregivers of these children. Telephone interviews were conducted over a one month period to a random sample of subjects from the various islands of the State of Hawaii. The CHIP questionnaire, developed by McCubbin et al. (1983), and a demographic questionnaire were the data collection instruments utilized. Despite methodological limitations, the findings can be of use to social workers in planning for efficacious service delivery.

The results of this study suggest a sample of children who were diagnosed as having congenital heart disease within the first year of life and who had no significant surgeries or limitations placed on their activity. The typical respondents were young married mothers who had a high school education and whose incomes were low given the cost of living in Hawaii. Most had used informal supports in addition to some public services, and most believed that their child would recover completely.

Thus, we have a sample of children who do not present extraordinary physical caregiving demands and a population of parents who seem to have the resources to manage their children without major difficulties.

The coping patterns that emerged from this sample of parents and were identified as extremely helpful focused on family integration followed by understanding the medical situation. The

dimension of social supports was found to be the least helpful of the three to parents.

All ethnic groups were found to display comparable coping patterns. However, geography seemed to display some impact in the the respondents from the Big Island were less likely to report understanding the medical situation as extremely helpful and were less likely to use formal support services.

Implications of these results for both social work practice and for further research are as follows. A family approach that documents client and parent characteristics is necessary in the assessment phase. Utilization of the CHIP questionnaire to document coping patterns also appears useful in clinical assessment. Engaging the entire family, especially the father early on is important if family integration is to be enhanced. A combination of strategies including verbal communication and written information to facilitate parental understanding of the medical situation can be employed.

Further exploration of the issues is needed using a larger and more diverse sample. The meaning of the pshychological burden or impact should also be investigated as well as how social support impacts on coping.

Finally, it is important to recognize that because of the complexity of human behavior, research does not usually generate new and innovative information. Rather, it tends to provide us with new directions for exploration, to raise more questions about the issue, to reinforce our practice wisdom, and to provide empirical support for the relevance of social work practice with families with children with congenital heart disease.

Table 1
Characteristics of the Child with
Congenital Heart Disease

Age	Range Less than 1 year to 17 years Mean 5 years
Age at Diagnosis	93% diagnosed at birth
Gender	56% male 44% female
Significant Surgery	62% none 34% one or more
Activity Limits	81% none by parents 84% none by physician
Medications	87% none
Clinic Visits	62% less than once a year

Table 2
Summary of Characteristics of
Respondents

Relationship	81% mothers
Age	Range 20 years to 65 years Mean 34 years
Marital Status	65% married
Income	90% less than $21,000.00 per year
Family Size	66% four or less
Education	Range 6 grades to College Graduate Mean High School Graduate
Residence	53% Oahu 18% Kauai 15% Hawaii 12% Maui
Religion	43% Catholic 21% Protestant
Ethnicity	25% Hawaiian/Part Hawaiian 22% Filipino 18% Mixed 12% Caucasian 12% Japanese
Informal Support	84% readily available
Community Resource	72% using public agency services
Degree of Recovery	61% complete 26% stable but will always require followup
CCSB Services	N = 22 medical care most useful N = 12 public health nurse most helpful N = 10 financial assistance most helpful

Table 3
CHIP Items of Subscale 1

Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation

Identified and Extremely Helpful

Item		Percent
C1	Trying to maintain family stability	59%
C3	Trusting my spouse to support me and the children	65%
C6	Believing that my child will get better	75%
C8	Showing that I am strong	59%
C16	Belief that the clinic has my family's best interest in mind	72%
C18	Believing in God	84%
C21	Doing things as a family	69%
C23	Believing my child is getting the best medical care possible	90%
C26	Telling myself that I have things to be thankful for	81%
C31	Encouraging my child to be more independent	59%
C36	Building a closer relationship with my spouse	62%
C38	Investing myself in my children	75%
C41	Talking over personal feelings with my spouse	59%
C43	Having my child seen at the medical clinic on a regular basis	72%
C44	Believing that things will always work out	75%
C45	Doing things with my children	87%

Table 4
CHIP Items of Subscale 2

Maintaining Social Support, Self-Esteem, and Psychological Stability

Identified as Extremely Helpful

Item		Percent
C17	Building close relationships with people	62%
C19	Developing myself as a person	75%
C27	Becoming more self reliant and independent	56%
C32	Keeping myself in shape and well groomed	62%

Table 5
CHIP Items of Subscale 3

Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff

Identified as Extremely Helpful

Item		Percent
C5	Talking with medical staff (nurses, social workers) when we visit the clinic	72%
C10	Talking with other parents	59%
C15	Talking with the Doctor	75%
C35	Being sure the medical treatments are carried out at home	68%
C40	Reading about the medical problem which concerns me	53%

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